

LQA Summary Data: **Trends, Issues and Needs** **FY 2001/02**

Introduction

Since 1997, the Area VI Board has conducted Life Quality Assessments (LQA's) for individuals who use regional center services living in the area of Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne counties. These assessments, or LQA's, are intended to capture the individual's perspective on the quality of his or her life, to enrich the individual's planning process. In addition, the LQA summaries provide an overall view of the issues, concerns, and needs experienced by adults and children with developmental disabilities who live in situations other than with their families of origin. As part of the Area Board's mandate to identify issues and needs for persons with developmental disabilities, the LQA Summary data results have also been reviewed in aggregate.

Just as the individual summaries are intended to contribute to but not supplant an overall planning process, so this report is intended to be one tool in the information gathering and assessment process that underlies effective resource development. LQA data is highly subjective, reflecting as much as possible the individual's self perceptions at the time of the visit. The more successful the visitor is in catching that perception, the more useful the LQA is in informing the individual's planning team of personal needs and concerns. Trends in aggregate data represent common experiences, and as such, provide vital insights into the service system and generic support systems in our communities.

Project Design

The format, methods, and standards for conducting LQA visits used by the Area VI Board have all been developed by DDS and are standardized throughout the State of California. Area VI Board relies primarily on trained volunteers, who receive a stipend for completing summaries, anticipating generating over 12,000 volunteer hours over the duration of this three year project cycle. The project is managed by a full-time LQA Coordinator, and supported by a half-time Office Assistant. Halfway through this fiscal year, the project was expanded by a second Community Program Specialist position, related to the rapid growth in the Board's catchment area.

LQA Summary Results

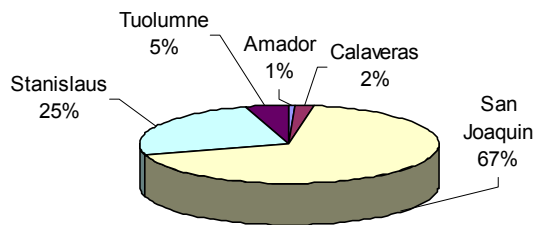
Aggregate Data Reporting Format

The LQA process looks at 25 life outcomes, grouped into six areas. For each outcome, the visitor indicates either "OK at this time" or "Needs Follow-up", and then documents the observations and comments that explain their conclusions. "Needs Follow-up" is indicated for several reasons. The visitor may not have been able to observe any information about that particular outcome, so the status is unknown. "Needs Follow-up" can also reflect known issues that are being addressed but not fully resolved, or issues that most probably can't be changed but rather reconciled, such as physical losses related to aging.

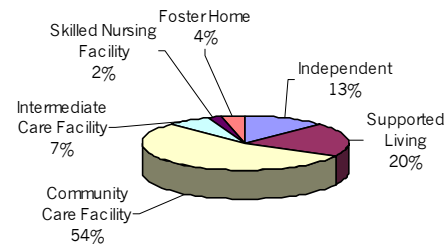
Overview

During this year, visitors and LQA staff completed 525 visits, and attempted to complete an additional 340 visits. The attempted visits were not completed for a variety of reasons, such as a major illness or incarceration. People also declined to have visits, sometimes because of satisfaction with their lives and sometimes because of personal crisis. Visitors and staff were also unable to contact 55 individuals. For each of those individuals, Valley Mountain Regional Service Coordinators were helpful in efforts to make contact. By far the majority of Service Providers were also very supportive of each person's right to have a Life Quality visit.

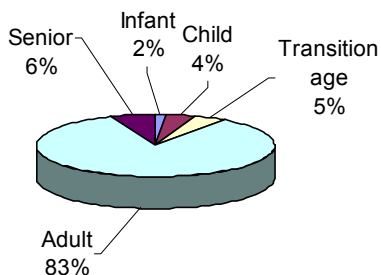
As in past years, visitors found that most of the people they visited are in safe situations and that their basic needs are supported successfully. The living arrangements and supported day time activities varied through a wide range of service options. Visits were conducted in all five counties of the VMRC catchment area, and both adults and children living in situations other than with their family of origin were visited. People who were visited during the first year of the project were contacted for repeat visits this year. Visitors usually found that issues raised in the previous visit had been addressed, particularly those who had had potential rights violations, and saw significant improvements in the quality of day time activities and home life for those individuals.



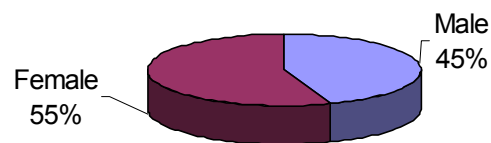
Visits by County



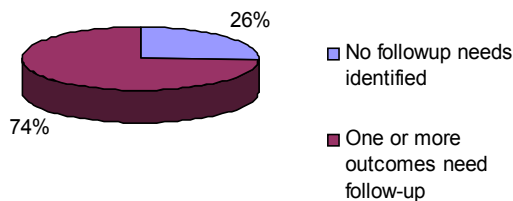
Type of Residential Services



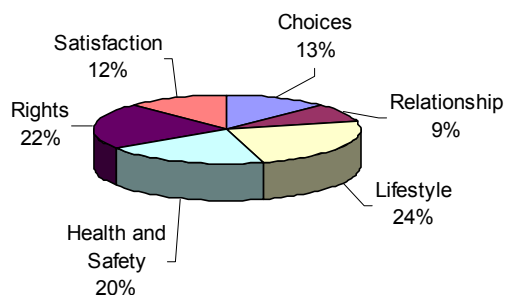
Age of Person Visited



Sex of Persons Visited



LQA Identified Follow-up Needs



Needs Identified in Outcome Areas

Choice

The “Choice” category includes information about the ways that individuals identify their needs, wants, likes and dislikes; how they make major life decisions; how they make everyday decisions; the role they have in selecting providers of services and supports; and how their services and supports change as wants, needs and preferences change.

Communication continues to be the most frequently identified as a barrier to making choices. Visitors are finding increased use of assistive technology and increasing use of options such as switches and similar items that can be installed in key environments. Visitors also noted an increased use of sign language. For one individual, the discovery that he could learn sign language was making rapid improvements in the quality of his life. Eighteen individuals had problems with communication systems, including systems only available in one life setting, broken communication devices, and, in one instance, a delay of over two years with equipment still not procured. Support staff often relied on ability to interpret the individual’s personal communication relationally and without assistive tools, and often did not express concern about the dependency that engenders. Sign language consistency across environments was raised as a concern for 5 individuals.

Most people living in their own homes expressed satisfaction with the choices that they made in their lives. Ten percent of the individuals who were able to communicate to the visitor with words and who were living in residential facilities related problems with limited choices, particularly in the areas of food and activity options. Other concerns related to room decorations, roommate selection, and service providers. Fourteen individuals expressed a desire to change services providers. Nineteen people, who were otherwise unrestricted in their right to make decisions for themselves, stated that they didn’t agree with decisions that are made for them by family, staff, and in one instance, the Service Coordinator. The range of choice options continued to vary among service providers.

Relationships

The Relationships category includes information about individuals’ friends and caring relationships; and whether they have community supports that can include their family, friends, service providers, other professionals, and other community members.

Relationships are always central to the quality of an individual's life, and are frequently areas of concern. Unlike previous years, however, the majority of concerns did not fall in this category. In total, relationship concerns were identified for nine percent of the people visited, across age groups and residential settings. The desire to find or spend more time with family was the most commonly expressed issue. Visitors commented on the frequent attempts by many careproviders to involve family in people's lives, and their excitement when family responded. Service Coordinators had also tried to locate family for individuals as well. Follow-up on lack of family involvement had not been done on behalf of the individual in only one instance. Twenty-four individuals expressed loneliness and a desire for friendships. Nine wanted to visit out-of-area family and friends. Eight individuals identified significant conflicts with their roommates, including three who had been assaulted by their roommates. Three others had been assaulted by housemates. Three people wanted their own phones. Two people identified a need for Spanish-speaking friends. Six individuals shared the desire to spend more time with their children. Other concerns included marital difficulties, building community relationships, dating, and personal barriers to relationship.

Visitors noted that violence between partners was viewed as domestic violence, while violence between housemates or classmates seemed to be viewed as a behavioral issue rather than an abuse issue. They raised the question of the overall impact on relational quality for people living in households where they felt physically threatened, not only with that individual but with all relationships. They also raised concern for children who had frequent relationship changes due to changes in residential settings and housemates.

Lifestyle

Lifestyle is a broad category, including if the individual is part of the mainstream of the community; if their lifestyle reflects cultural preferences; if they are independent and productive; if they have stable living arrangements; if they are comfortable where they live; and if children who are regional center clients live at home with their families. In part because of the range of the lifestyle category, the greatest number of concerns were identified under this category, from 50% of the people visited. As in previous years, issues ranged from small changes to lifestyle reordering.

Although the majority of people expressed satisfaction with day program services, visitors found an increase in those who expressed dissatisfaction with day program services. Nine percent of the adults visited expressed specific desires to change day program services. The common themes were wanting more activity, more community involvement, and paid work as part of the program day. Support staff raised concern for one individual who did not use words and who prefers a quiet environment, but is in a program that is often noisy. Twenty more individuals identified things that they would like learn, such as a particular craft or life skill. In addition to those specifying work as part of a day program service, 55 people, 13% of the working age adults visited, talked about work related needs, either getting a job, increasing hours on a job, or changing jobs. For those who wanted to work, the concerns varied. In a few instances, people wanted a volunteer situation, some had significant barriers to employment, and some just wanted increased income. Most of these individuals had already begun discussing their preferences with their planning teams.

Cultural needs were identified in visits with 33 individuals. As in previous years, visitors observed that providers were generally making efforts to build cultural elements into the services they offered through menu offerings, activities, and home decor. While various cultures tended to interject into an Anglo-American milieu, none were the dominate lifestyle. For example, favorite Mexican-American dishes might be included in an Anglo-American menu, rather than the reverse. Six individuals expressed the desire to live in dominantly Mexican-American settings. No community care facility visited used Spanish as the common language within the home. Cultural needs were also expressed for individuals of Hmong, Laotian, Irish, and Syrian descent.

An unexpected result this year was the number of people who expressed a desire to attend church, 8% of the adults visited. Barriers included transportation, distance from preferred church, no staff support to attend preferred services, and a preference to worship in a community church rather than through ministerial visitation to the home. Two individuals shared that they wanted to change their homes because recent moves had taken them away from their home churches, and felt that their church preferences were not part of the planning team decision-making process.

Social/recreation needs were also often cited. Ten percent of adults and youth expressed the desire for more activities in the community, particularly on evenings and weekends. Specific requests included bowling, shopping, going to concerts, and travel out of the area. Three individuals identified access barriers related to wheelchairs and ramps. Three parents identified needs for family recreational resources.

Most people expressed satisfaction with the transportation they were able to access through public transportation or from their care providers. Public transportation services continue to expand in most urban areas. Individuals receiving supported living services were generally very satisfied with the help they received to travel to appointments, shop, and conduct other business in the community. Three individuals in rural settings had problems with no public transportation available to them. Two individuals spent more than 3 hours each day on buses to and from their day programs.

With the exception of 15 individuals visited, people were settled in stable housing. It is unknown how many of the attempted LQA's were not completed because of instability in housing, as that was undoubtedly a factor for many of the individuals who could not be reached. Housing instability was related to finances, substandard housing, domestic violence, and for three individuals, pending closure of their residential facilities. Two teens had concerns about being forced to move after they transitioned to adult services, and two children were in short-term emergency housing due to behavioral intervention issues when contacted for their LQA visits.

Eighty-two individuals, 16% of those visited, had issues regarding the comfort of their homes. Fifty-three of these individuals lived in a supported or independent situation, and had problems typical of low-income housing. Household repairs, crowding, and drug-related activities in the neighborhood were among the most common problems. Some issues were specific to disability-related needs, including bathroom accessibility for two individuals and assistance with household maintenance. Parents also had needs for their children. Two

identified needs for play areas, and three for a larger home. Five people wanted to purchase their own homes. For those living in residential facilities, the needs most often raised related to relational concerns, the desire to be in a different neighborhood, changes in routines, and specific items such as a repair of a TV set. Visitors found that children were in comfortable homes with attentive and involved foster families. Cultural differences were significant for one Mexican-American child, and as mentioned, two children were in crisis placement at the time of the LQA contact.

Health and Well-being

The trend of increased medical and safety issues continued for the second year. In total, 20% of the identified needs this year were related to health and safety needs. It is important to note that the individual's Service Coordinators were usually aware of these concerns and many were not immediately resolvable through regional center intervention. Most people visited had prompt medical care in response to their health needs.

Eighteen individuals stated that they did not feel safe in their neighborhoods, related to crime activity. Three of these individuals expressed a sense of particular vulnerability due to their use of wheelchairs. Two individuals were in spousal domestic violence situations. Substandard housing, such as unsafe wiring, presented immediate safety issues for 3 individuals visited. Two individuals had behavioral concerns that were creating risk for them in their apartments, and one individual needed training in proper use of a stove to prevent fire hazard. Five individuals had inadequate safety accommodations to their homes, including a broken ramp, barred windows, no grab bars in the shower, and inaccessible bathtub. Six people living in residential facilities said that they did not feel safe in their homes, and two people said that they did not feel safe at their day programs. Six individuals related incidents of being assaulted by housemates, three of whom were also roommates. They were fearful of being assaulted again. One person did not understand why the assailant had not been asked to leave. Two individuals expressed fear of particular residential staff persons. Four facilities visited had rooms that would be very difficult to exit in emergency, because of furniture arrangement or having only one exit in the bedroom.

Ninety-eight individuals identified one or multiple wellness or health concerns. Nineteen of these complained of chronic pain, and it was not clear what pain management options had been explored for the individuals. Visitors found seven individuals who were experiencing recent health changes, such as increasing weakness, that were thought to be related to aging or progression of known illnesses, and were to be discussed at upcoming planning meetings. Nine people had had recent medication changes that caused significant side effects including nausea, vomiting, excessive sleepiness, and dizziness. In each instance, side effects were reported to have been going on for several weeks. Four people had health problems exacerbated by situational problems, such as staff smoking, house temperature, and food allergies. Risk behavior was noted by visitors for 6 individuals. Three people complained of dental pain. Ten people described chronic sleep disturbance over a prolonged time period. In one instance, the person confided that the roommate's TV was too loud. In nine instances, visitors observed inadequate staff response to personal care needs such as not responding to a person's request for assistance to go to the bathroom, or differences between the home and day program understanding of the individual's personal care needs. Three people had infections or minor injury that had not been medically evaluated at the time of the visit.

In addition to health problems, people also expressed the desire for wellness activities. These included exercise, smoking cessation, counseling, and weight loss. In one instance, support staff asked how a copy of medical records could be secured for the individual. One parent also asked for that information.

Twenty-five individuals had needs regarding protecting their own health and safety. Most commonly, people wanted to understand why they were taking the medications that they were taking, learn about 9-1-1, practice fire drills in their own home, or know what to do in an earthquake. Two people wanted self defense classes.

Ninety-two people identified a need for medical services that they did not currently receive, across all counties. Twenty-one people stated that they needed a dentist, needed a dentist who accepted Medi-Cal, or, in two instances, only had access to a dentist with a long waiting period before appointments. Eighteen people stated that they were unable to get the counseling or mental health services that they wanted. Ten people needed wheelchair repairs, which would be discussed with their planning teams, and 8 people needed other medical equipment such as a hoist lift. People also had problems with health coverage. Two had none, and five had needs for medications or treatment that were not covered by their insurance plans. Only three people said that they needed a primary care physician, and three people said that they wanted a different doctor for personal reasons. Twenty-five people identified needs for specialists, including physical therapists, gynecologists, oncologists, neurologists, or speech therapists. One person expressed the need for an AA group designed for persons who use regional center services. Two people needed transportation for medical treatment outside their home communities.

Rights

The Rights area of the LQA gathered information on the individual's exercise of personal rights as a person who uses services and as a citizen; whether or not the individual is free from abuse, neglect and exploitation; if the individual is treated with dignity and respect; if the individual is receiving appropriate generic services and supports; and if the individual has advocates or access to advocacy services.

The understanding that individuals had regarding personal rights varied widely, and was not necessarily related to the degree of supports being provided to that individual. As in previous years, most visitors observed respectful and even affection interactions between individuals and the people who support them. Unlike previous years, however, the percentage of rights issues identified overall was higher, identified for 22% of the individuals visited. By far the majority of these needs related to the individual's desire to understand their rights and services better, and to assert themselves more effectively, rather than to any restriction of personal rights. Sixty-two people expressed such an interest and may actually reflect increased understanding regarding the importance of their rights for many of those individuals. Visitor also found that while some people could indicate rights posters, they did not make the connection to ways that they could use those rights for themselves. Four people wanted to register to vote. Other issues included increased privacy, less restrictive rules, Landlord/Tenant rights information, staying home alone, access to personal belongings and communication devices, and control of personal spending money.

Twenty individuals alleged violations of their rights that were potentially abusive or exploitive. Five of these complaints involved support staff, and one involved an extended delay in provision of necessary medical equipment. Six people complained of assault by housemates, three of whom were also roommates. One person had a complaint against a landlord, and the remainder of complaints involved family members.

Forty-six individuals raised issues related to being treated with dignity and respect. Sixteen people identified one or more supports persons as being disrespectful in their use of language, attitude towards privacy, and acknowledgement or honoring of personal preferences. Visitors identified three instances where adults or teens were addressed with “baby talk” or had room decorations typical of very young children. Eleven people felt disrespected by peers, one by a bus driver, two by community members, and one by a landlord. Three individuals felt disrespected by Service Coordinators, by language or perceived non-response to requests. The remaining individuals had family difficulties.

Many people visited were using generic services and supports successfully. As discussed previously, visitors found that more public transportation services were available to people in urban areas. Thirty-seven people identified problems with generic resources. Most of these needs involved information about social security benefits, Section 8, transportation in rural communities, and accessing various social services. Five parents identified parenting support needs, including activities during school breaks, parenting skills training, and respite.

Eighty-two people expressed concerns related to advocacy services, including legal services. Fifteen people asked for help resolving various life problems or accessing services, including victim witness services, transportation barriers, and trust fund access. Twelve people had specific legal needs related to domestic violence, divorce, Landlord/Tenant rights, and child custody. One individual requested assistance in removing a parent as conservator. Four individuals had concerns related to support staff advocating on their behalf.

The remaining issues related to Service Coordinators and VMRC services. Some of the issues raised were matters of personal preferences, for example wanting a Service Coordinator who was male, or female. Other issues related to understanding the role of the Service Coordinator. One person felt like the Service Coordinator could not hear well enough to understand speech, and four people felt that the Service Coordinator had been disrespectful or unresponsive in some way. The majority of complaints fell into three areas – frequent turnover of Service Coordinators, slow response, and unsatisfactory accounting information regarding personal funds. This latter issue has been identified each year of the project. Two people also complained that their checks were being sent to the wrong address.

Satisfaction

The Satisfaction area of the LQA addresses whether or not individuals achieve personal goals; if individuals are satisfied with services and supports; and if individuals are satisfied with their lives.

Satisfaction was often a difficult outcome for visitors to assess. As would be expected, often people were happy with some aspects of their lives and not with others. For the most part, individuals visited expressed satisfaction with their lives. Most of the people visited lived in attractive and comfortable settings, and felt that they were supported with care and respect.

Twenty-six percent of the people visited indicated no areas of concern. Of those who either shared concerns personally or had family or support staff share concern for them, most had already informed their Service Coordinators. As stated earlier, issues were also related to personal perception, and many issues, like the desire to have more friends, were circumstances that might not be immediately resolvable through regional center services.

Visitors especially enjoyed learning about the many dreams that people had for their lives, and 87 of the people visited shared one or more. People wanted to get married, have children, own their own homes, and get quality jobs. Being able to drive was a dream for 18 of the people visited this year. Individuals also had dreams specific to their own talents and ambitions, such as writing a book, or working with people who have disabilities. Caring for aging parents continues to surface, in this year, two individuals talked about their long range plans to care for their parents.

In addition to issues already discussed, people talked about wanting different kinds of services, new day programs, different workers, and people who could help them achieve their ambitions. Three people wanted to move out of their home community, expecting that services would be better in another region of the State. In addition to those issues already discussed in this report, 29 people expressed dissatisfaction with one or more support staff or service agencies. Visitors also noted the individuals with patterns of very different affect and interaction in their homes as compared to their day programs and raised the question if such differences related to satisfaction with one or the other services. Twenty-three people visited, 4% of the total, were best described as experiencing overall unhappiness with life. For some of these individuals, known mental and physical health needs were most probably related to their dissatisfaction with life. Others had frustrations tied to family, legal constraints, and other life circumstances. A few felt so unhappy with some part of their lives, such as their home placement or day activities, that they were unable to focus on any other topics during their visits.

Visitor Remarks

Visitors noted a continuing trend to improve the appearance and comfort of many homes. They also found new day programs and day programs with changed formats. Support staff were generally very cooperative with the LQA visit process. Most of the people they visited were either very happy and somewhat happy with their lives.

Visitors also raised questions about the expanded number of large residential facilities, or networks of several small facilities owned by one provider. People visited tended to spend their lives within those facilities or networks more exclusively. Visitors also noted the frequency that activities typically done in the community, such as haircuts or worship services, were instead being done by bringing someone into the home. As previously discussed, visitors questioned the viewpoint that does not define or respond to housemate violence as a domestic violence issue.

Conclusion

Aggregate data from the Life Quality Summaries is necessarily moderated by the anecdotal and subjective nature of the tool itself. The process is designed to be highly individualized, and to reflect information that might not otherwise be gathered, including the individual's own

perspectives on his or her life. As in previous years, the overwhelming conclusion of the data is that people are, for the most part, being supported in ways that meet their needs respectfully, effectively, and even joyfully. Some trends, such as the number of people wanting to know more about rights, may actually indicate increasing awareness of rights. Increased transportation services and economic opportunities also enhanced quality of life.

The number of issues raised related to health is a two year trend, and may be related in part to the impacts of managed care. Certainly, difficulties accessing mental health, dental services, and specialists merit further consideration of that possibility. Problems getting second opinions, alternative health care, and wellness activities such as prostate exams also raise questions both about access and provider bias.

The rapid growth in the San Joaquin Valley has significantly impacted the cost of housing. Renting and home purchase are becoming more difficult. Supported living staff shared the increasing difficulty of finding affordable housing in desirable neighborhoods, a problem that has emerged in the aggregate LQA data as well. Rising costs also impacts hiring and retention for service providers, and it will be worthwhile to monitor any trend regarding concerns about staff turnover in aggregate data. This concern was expressed with particular intensity by biological and foster parents of young children this year, but in numbers too small to indicate trends.

As discussed previously, the number of persons expressing dissatisfaction with day program services increased. As is always true, the variability of individual circumstances and the idiosyncratic intent of the tool itself advise against quick conclusions. Visitors also found individuals who had made changes in daytime services and who were extremely satisfied with what was now available to them. If the trend continues, further information gathering and analysis would be warranted. Size and insularity of residential services are also trends that merit consideration. Again, the primacy of cultural and religious preferences is problematic. While providers were making real effort to incorporate cultural elements into their services, culture appeared to be secondary rather than primary in planning team decisions and service design.

